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ABSTRACT

This report is the product of a committee charged to define "medically fragile," explore the array of educational services available and/or needed for children in Michigan considered medically fragile, identify current information and gaps in the information, and identify areas of interagency collaboration. The report discusses critical evolving issues, including definition of the term "medically fragile," demographics of this population, and legal precedence for educating medically fragile students. It also discusses partnership and communication issues through vignettes focusing on the family's perspective and needs and emphasizing interagency cooperation. A section on program support recommendations outlines specific steps in service delivery and discusses transportation issues, nursing needs, and staff training. Appendices contain a bibliography of reports and books (15 entries), a list of approximately 45 audiovisual materials, and a list of health care occupations to consider as potential resources for training school employees. (JDD)

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# Mechanically Produced Cheese

## A Report from the

## State Committee on

## Mechanically Produced Cheese

## Research Group

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# Medically Fragile Children:

**Report from:**

**State Committee on**
**Medically Fragile Child**
**Referent Group**

**August 1991**

This document has been developed by the State Committee on Medically Fragile Child Referent Group as requested by the Michigan Department of Education, Special Education Services to assist the public in understanding this population of children.

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# Section I

## A. Acknowledgements

It is not often that both heart and mind can be blended together to produce a significant document and to move a body of information forward for a significantly important group of young people in our state. However, this document represents the product of just such a happening.

In September 1989 Dr. Edward Birch, then Director of Special Education for the State of Michigan, brought together a diverse group of individuals representing parents, educators, university professors and trainers, ancillary staff, and administrators. He asked this referent group to review and meet a four-point objective concerning the child who is considered "medically fragile." The group accepted the responsibility for the state and began a journey that is still ongoing.

In the 1989-1990 academic school year, the referent group met for nine formal, all-day sessions in Lansing. Five subcommittees were organized and met individually and through correspondence to arrive at their conclusions. Each member of the group committed in excess of 100 hours of service, striving to reach concensus on all of the points listed in this document.

The referent group members are as follows:

| | |
|---|---|
| Leonard Rezmierski | Chairperson, Director of Special Education, Northville Public Schools |
| Roberta Anderson | Assisstant Professor of Special Education, Eastern Michigan University |
| Judy Barnes | Parent |
| Agnes Bellel | Consultant, WCRESA |
| John Bretschneider | Supervisor, Gratiot-Isabella RESD |
| Ron Greiner | Consultant, Washtenaw Intermediate School District (ISD) |
| John Johnson | Director of Special Education, Gogebic-Ontanagon ISD |
| Beverly McConnell | Parent |
| Gerald Nester | Coordinator, Field Services Program, Special Education Services, Michigan Department of Education |
| Janice Richards | Director of Special Education, Farmington Public Schools |
| Deborah Russell | Parent |
| Sharon Satterfield | Teacher, POHI Program, Grand Rapids Public Schools |
| David Soebbing | Supervisor, Wayne County Regional Educational Services Agency (WCRESA) |
| Tina Tefft | Teacher, High Point Center, Washtenaw ISD |
| Karol Zeliff | Principal, Croyden School, Kalamazoo |

We are all very pleased and honored to have been given the opportunity to produce this work for our state. It is also important to note that the final document took longer to produce than the group originally anticipated. This was due, in part, to ongoing legal cases and other matters of significance to the body of this information. All of this work was uniquely reorganized and synthesized by Dr. Virginia Rezmierski, Educational Psychology Consultant. To all of these individuals, I owe a tremendous debt of gratitude. I not only have learned to appreciate the diversity and talent in this state, I have learned the truth in the statement that "when people of good will are brought together, good will be produced".

This document serves as testimony to all of our efforts on behalf of children in the State of Michigan. We sincerely hope it finds its place and value in every school district and related agency in our state.

Sincerely,

Leonard R. Rezmierski, Ph.D.
Chairperson, State Medically Fragile Referent Group

## B. Introduction

### Charge

On September 12, 1989, Dr. Edward L. Birch, recognizing an increasing need for services, emerging legislation, and an absence of guidelines in this area, convened a Medically Fragile Referent Group consisting of educational providers and consumers. He charged the committee to:

1. Define "medically fragile;"
2. Explore the array of educational services available and/or needed;
3. Identify current information and gaps in that information; and
4. Identify areas of interagency collaboration.

Dr. Birch requested that the report be completed by June 1990 for dissemination to Michigan administrators and boards of education.

Since the completion of this report extended beyond the originally targeted completion date, the referent group has updated the legal information to June 1991.

### Mission Statement

Since medically fragile students in Michigan have the same rights to quality education as any other student, the referent group believes that all necessary and required educational services need to be identified and provided.

## Section II

## Critical Evolving Issues

## A. Definition

The referent group reviewed multiple documents as it began its study of this topic. The documents reviewed by the group included: 1) the 1989 Report of the Census of Children With Complex Health Care Needs and the Survey of Families Who Care for Them; 2) the 1989 Special Focus Report: Current Perspectives on the Education of Medically Fragile Students; 3) the 1989 Medically Fragile Subcommittee Report from the Wayne Intermediate School District; 4) the 1986 Policy Research Paper entitled, "Handicapped Children" from Great Lakes Area Regional Resource Center; 5) the Council for Exceptional Children 1988 Ad Hoc Committee Report on Medically Fragile Students and 6) various other documents. All references are listed in Appendix A of this report. Each of these documents suggests language and definitions which attempt to specify this population.

Working definitions of the term "medically fragile" have been developed by various groups. The language contained within the various definitional efforts has proven helpful in understanding the scope and variability of conditions included in the term "medically fragile." Some concepts have been paraphrased and are included here because they provide background and further contribute to the definition used in this report.

1. "Report of the Census of Children with Complex Health Care Needs and the Survey of Families Who Care for Them" (July, 1989) (Prepared by Health Management Associates, Inc.)

Children who in the past might live only days or months are now having extended life expectancies; they are living into their teens and perhaps longer because of advances in medical technology and the attentive care they receive at home. These students require long-term health care. Due to the severity of their diseases and the complexity of their care needs, they are often given such labels as "technology-dependent," "medically fragile," and "severely multiply impaired."

2. Report of the Office of Technology Assessment on Technology Dependent Children, Washington, D.C., 1987.

Some children are labeled "technology-dependent" because of their reliance on life-sustaining medical technology. " A child in this group needs both a mechanical device to compensate for the loss of a vital body function, as well as substantial and ongoing nursing care to avert death or further disability. Nursing care may be provided by a professional nurse, a trained and skilled parent or other trained lay caregiver."

Some are labeled "medically fragile" because they are dependent on nursing care and medical devices for life support and/or maintenance of their current health status. These children require medical intervention, such as tracheotomy tube care, suctioning, oxygen support, or tube feeding. They may be dependent on nursing care and medical devices that compensate for body functions such as apnea monitors, renal dialysis, urinary catheters, colostomy bags, heparinization, and other specialized care. They may also require prolonged intravenous administration of nutritional substances or drugs.

Another group of children also labeled "medically fragile" requires intermittent to continual nursing care, monitoring, and some medical intervention for sustaining life and/or prevention of further disability. At one time these children may have required mechanical and device-based support. They may have frequent seizures, cease breathing, or require monitoring because of the drugs they receive. They may require frequent therapy, stimulation, or constant holding. These children might experience continual or frequent

pain or discomfort, vomiting, or loss of other bodily functions and control. They may have severe allergies and other immune system deficiencies. Children with ARC or AIDS may be in this group.

3. "Current Perspectives on the Education of Medically Fragile Students: A Special Focus Report" (February, 1989) (Prepared by the Center for Quality Special Education)

Children referred to as "medically fragile" are a diverse group of individuals. In the absence of a commonly held definition to categorize these children, they are best described on a case-by-case basis. Underlying each case, however, are medically fragile characteristics. For example, a medically fragile child may be one of these children:

a) a student with respiratory problems who has a tracheotomy that requires suctioning in order for the student to breathe;
b) a student who has apnea which requires constant monitoring to assure that breathing has not stopped; or
c) a student with a severe seizure disorder who must be given medication rectally in order to control the seizures.

Each of these cases defies a generic categorical definition; hence, the danger of stereotyping is eliminated when we think of the medically fragile child as an individual with specific, special health care needs.

4. "Medically Fragile Subcommittee Report" (March, 1989) (Prepared by the Wayne Intermediate School District)

Definition: The term "medically fragile" refers to persons with complex medical care needs who require technology, specific services, or some form of ongoing medical support for survival. This definition includes persons with severe chronic and progressive illnesses and severe disabilities. These persons can generally be classified in one of the following categories:

> Medically at Risk refers to persons who have chronic health conditions which may periodically become life threatening. Severe forms of chronic disease such as juvenile diabetes, seizure disorders, hemophilia, temperature regulating disorders, immune disorders and asthma may be included in this category.
>
> Technology Dependent refers to persons who require mechanical devices or special technological interventions to maintain or sustain life. Persons in this category may require routine or periodic assistance from trained or licensed nursing personnel. Additionally, they may require the availability of professional skilled nursing personnel for assessment of their medical status on an as needed basis.
>
> Medically Dependent refers to persons whose medical status requires trained and/or licensed nursing personnel immediately available to attend them. Additional skilled professional nursing assessment of their medical status may be needed as frequently as every one to two hours. Such persons may be able to live outside of a hospital or medical care facility, but are dependent on a high level of care and assessment in order to sustain life.

Criteria: The placement of a student within a category of medically fragile or the exclusion of a student from the general category of medically fragile, may be facilitated through the analysis of level of consequence, latency, monitoring, and training.

1) Consequence: The ramification of failure to provide intervention
   High: Ramifications that result in irreparable damage
   Low: Ramifications are those which can be rectified

2) Latency: The span of time between the identification of a need and the initiation of intervention
   High: Intervention must occur rapidly (less than 15 minutes)
   Low: Adequate time is available to utilize resources not immediately available

3) Monitoring: The intensity of visual observation required to recognize signals of need for intervention. (Does not refer to machine monitoring.)
   High: Need for ongoing visual contact to detect subtle physical cues
   Low: Can be accomplished within a group setting while performing other duties

4) Training: The relative level of training required of the person providing the intervention
   High: Performed only by licensed or highly trained person
   Low: Performed by unlicensed person following short training sessions

Definition Based on Need level: Utilizing the concepts of consequence, latency, monitoring and training, we may define three types of students based on their level of need/requirements as follows:

| Category | Consequence | Latency | Monitoring | Training |
|---|---|---|---|---|
| Medically at Risk | High | High | Low | Low |
| Technology Dependent | High | High | Low | High |
| Medically Dependent | High | High | High | High |

Note: A student would be excluded from the general category of "medically fragile" despite an anticipated high consequence when the latency, monitoring and training requirements are low.

5. "Medically Fragile" Handicapped Children: A Policy Research Paper. (Prepared by Great Lakes Area Regional Resource Center) (May, 1986)

The term medically fragile has a meaning similar to a chronic or acute illness, physical disability or other health impairment that can be extremely disabling or life-threatening. It is distinguished from other heath impairments because of the acuteness and severity of the problems that usually require prolonged or intermittent hospitalization, institutionalization, or homebound placement. Medically fragile children are medical-technology assisted children who are dependent on life-support equipment. The uniqueness and severity of each child's handicap requires that they be educated on a case-by-case basis. Frequent absences from school for medical treatment and therapy necessitate individualized educational instruction with related services either in the classroom, hospital, institution, or at home.

6. Report of the Council for Exceptional Children's Ad Hoc Committee on Medically Fragile Students. (March, 1988)

Students who have special health needs, who are medically fragile or technologically dependent, have survived catastrophic health events and need prolonged specialized health care. It is the consensus of the Committee that the term medically fragile is not appropriate, and thus the Committee provides a broad-based functional definition of this population:

"Students with specialized health care needs require specialized technological health care procedures for life support and/or health support during the school day. These students may or may not require special education."

### Summary Regarding Definition

The Michigan Medically Fragile Referent Group concluded that there is no commonly held definition within Michigan or within the United States for the term, "medically fragile." It proposes that in general and for the purpose of this report, (as in the Wayne County ISD usage), the term "medically fragile" refers to persons with complex medical care needs who require technology, specific services, or some form of on-going medical support for survival. The term may include persons with severe chronic and progressive illnesses and severe disabilities.

## B. Demographics

There have been no definitive studies completed as to the numbers of medically fragile students in the state or country. However, the following efforts provide insights into the demographics of this population:

1. In 1989, a Michigan Association of Intermediate Special Education Administrators (MAISEA) subcommittee on the medically fragile sent a survey to all Michigan school districts. Seventy-two program sites, representing 28 intermediate school districts, responded. Six hundred and eighty students were identified as medically fragile. The students were categorized as follows: severely multiply impaired (60%); physically or otherwise health impaired (25%); and trainable or severely mentally impaired (15%).

2. In 1988, the Michigan Department of Social Services contracted with Health Management Associates, Inc., to survey the numbers of children between birth and six years of age who required long-term care based on current and complex health care needs. The study identified 526 children. The authors caution that this figure underrepresents the actual numbers, particularly with minority/ethnic children and infants in neonatal intensive care units.

3. In 1987, the Report to Congress and the Secretary by the Task Force on Technology Dependent Children indicated the following estimates of technology dependent children:

| Defined Population | Estimated Number of Children |
|---|---|
| Group I: | |
| Requiring ventilator assistance | 680 - 2,000 |
| Group II: | |
| Requiring parenteral nutrition | 350 - 700 |
| Requiring prolonged intravenous drugs | 270 - 8,275 |
| Group III: | |
| Requiring other device-based respirator or nutritional support | 1,000 - 6,000 |
| Rounded subtotal (II + III) | 2,300 - 17,000 |
| Group IV: | |
| Requiring apnea monitoring | 6,800 - 45,000 |
| Requiring renal dialysis | 1,000 - 6,000 |
| Requiring other device-associated nursing | Unknown -- perhaps 30,000 or more |

The above figures are estimates. They tend to under-report the size of the population. Subsequent to the report, the State of California did an analysis of its Group III children in institutions. The results for that state were higher than previous estimates. (Conference proceedings, Serving Medically Fragile and Technology Dependent Children in the 1990's, 10/23-24/89.) The composite figure of 6,000 is therefore likely to be conservative.

### Summary Regarding Demographics

The Michigan Medically Fragile Referent Group concluded that while exact numbers are not known, and estimates tend to under-report the size of the population, medically fragile

students probably represent a small portion of the special education students in Michigan. They are typically found eligible for special education as severely multiply impaired, physically or otherwise health impaired, or mentally impaired.

## C. Legal Overview

The review of legal precedence for educating medically fragile students is necessary since many of the practices that are currently in place have evolved as a result of litigation. This review will highlight the landmark decisions that are currently impacting the education of this population.

### Regarding "Appropriate Education"

In 1982, the U.S. Supreme Court in Board of Education Hendrick Hudson Central School District v Rowley, 458 U.S. 176, **established limits on the meaning of a "free, appropriate public education"** and defined the role of federal courts under the Education of All Handicapped Children Act (EAHCA) of 1975. The court ruled that an appropriate education provided specialized instruction and related services which are individually designed to provide educational benefits to a handicapped student at no cost to parents. The ruling also specified the federal courts' role to assure 1) that the procedural safeguards built into EAHCA are followed, and 2) that each individualized plan is reasonably calculated to enable the student to receive the benefit of an education.

In 1983, another important decision was made. In Roncker v Walter, 700 F.2d 1058, the Court of Appeals in the Sixth Circuit (including Michigan) placed severe restrictions on educating handicapped students in other than regular education buildings. The ruling stated that whenever feasible, handicapped children should be afforded contact with nonhandicapped peers in the least restrictive environment.

In 1989, the Court of Appeals for the First Circuit, in Timothy W. v Rochester School District, 875 F.2d 954, ruled that all handicapped children, regardless of the severity of the handicaps, are entitled to special education. The school district took the position that the child's handicaps were so severe (developmental disabilities, spastic quadriplegic, cerebral palsy, seizures and cortical blindness) that he was incapable of benefiting from an education and was, therefore, not entitled to one. **The court found that the Education of All Handicapped Children Act applied to all children regardless of their potential to learn.** The Supreme Court elected not to review this case and, therefore, it is binding on the districts in the First Circuit.

### Regarding "Related Services"

In 1984, the U.S. Supreme Court, in Irving Independent School District v Tatro, 468 U.S. 883, decided that clear intermittent catheterization (CIC) for a child with spina bifida was indeed a "related service" that had to be provided by the schools rather than a "medical service" provided by a medical organization. The court determined that schools are not responsible for "medical services" except for purposes of diagnosis and evaluation. The court also presented a three-step test to distinguish allowable "related services" from more restrictive "medical services": 1) to be entitled to a "related service," a child must be handicapped under EAHCA so as to require special education; 2) only those "related services" necessary to aid a handicapped child to benefit from special education must be provided; and 3) the "related services" must be provided only if they can reasonably be performed by a nurse or other qualified person (and not if they require a physician). **In this decision, the Supreme Court expanded the concept of "related services" beyond what many educators had previously considered to be related services for which educators were responsible.**

In 1987, Detsel v Board of Education of the Auburn Enlarged School District, 820 F.2d 587, cert den 108 S.Ct. 495, a federal appeals court in New York held that constant nursing care went beyond the scope of "related services." (The student required constant respirator assistance with a continuous supply of forty percent oxygen medication through a tube to the jejunum, tracheostomy mucus suctioning and possible CPR procedures.) The court decided that **the extensiveness of the health therapies made them medical in nature** and, therefore, not considered related educational services.

In Bevin H v Wright, 666 F. Supp 71, (1987), a U.S. District Court in Pennsylvania held that full time individualized nursing services for a multiply handicapped child were allowable under EAHCA. (The child has Robinow syndrome, severe bronchopulmonary dysplasia, profound retardation, spastic quadriplegia, a seizure disorder, hydrocephaly, and is legally blind. She breathes through a tracheostomy tube and is both fed and medicated through a gastrostomy tube. These conditions required full-time nursing assistance, even during transportation.) The court determined that these services were "medical services" not "related services" because of the cost, approximately $1850/month, and the nature of the services needed. Therefore, Detsel and Bevin H state that in situations **where the amount of "related services" becomes so pervasive that all of the district's efforts are directed to provide them, that provision is beyond the scope of "related services."**

But in 1989, a Michigan federal district court decision, in Macomb County Intermediate School District v Joshua, 715 F. Supp. 824, found that a severely multiply impaired student (who required a "halo" to hold his head upright, tracheostomy suctioning approximately every 15 minutes, and had rigid limbs in danger of easily being broken) must be transported to school in a vehicle with a lift and an aide to suction his tracheostomy at the expense of the local district. The court interpreted the services needed by this student as "related educational services" and **"medical services" as only those services provided directly by a licensed physician**, thereby rejecting the rationale of Detsel and Bevin H.

In Macomb Intermediate Federation of Teachers v Macomb ISD, Macomb Circuit Court File No. 88-2474-CZ (March 20, 1991), the plaintiff union held that such services as intermittent catheterization, tracheostomy care and oral and nasal suctioning, while required to be provided by districts under EHA, were not delegable under the Public Health Code and, therefore, could not be provided by teachers and aides. The courts rejected this argument, stating that the patients under question were in stable condition, not unstable as in hospitals. Therefore, because they were stable and in need of these services for maintenance, **the services were delegable within the parameters of the Public Health Code**. "Specifically, **they can only be delegated by a medical licensee, must be delegated to an individual who is qualified by education, training or experience, and delegated to a person under the licensee's supervision."**

### Regarding Staff Liability

In regard to district and staff liability, it is important to consider Johnson v Clark, 165 Mich App 366 (1987), heard in the Michigan Court of Appeals. This case found that damages are not available against school employees for evaluations, misplacements, or educational malpractice under EAHCA, Section 504, or even common law. The Tort Reform Act of 1986 grants immunity from claims of negligence if school personnel perform actions defined within the scope of their employment and authority (as long as "gross negligence" is not shown). However, employees may incur liability if acting outside their scope of practice/authority or if an intentional action to hurt can be demonstrated. In addition,

Brooks v St. Tammary, 510 So.2d 51 (LA App. 1 cir. 1987), indicated that increased liability does not follow if districts incur added risks in providing care for a medically fragile child within a school setting.

### Summary Regarding Legal Precedence

In summary, Rowley established limits on what constitutes an appropriate education; Roncker required mainstreaming; Timothy W determined handicapped children entitlement to a free appropriate public education; Tatro defined "related services" to include some services that were previously considered medical in nature; Macomb Intermediate Fed. established that the specialized support services are delegable; Detsel and Bevin H. found that the pervasiveness of "related services" can make the services more medical in nature; Joshua stated that "related services" may include the presence of a medical professional other than physician during specialized transportation; and Johnson & Brooks established limits on liability.

These cases, up to March 1991, established legal considerations which must be taken into account when deciding appropriate placements for medically fragile students. They illustrate evolution and expanded understanding of school district responsibilities pertaining to educating medically fragile students, particularly what constitutes "related services" versus "medical services." This is an area of active litigation with modifications occuring at any time. Therefore, parents and district personnel need to be constantly aware and informed regarding legal developments in this area.

## Section III

## Partnership/Communication Issues

## A. A Family's Perspective and Needs

### Vignette I.

Tommy and his twin sister were born seven weeks premature. Following respiratory distress, Tommy was placed on a ventilator and oxygen. He had various types of feeding tubes, intravenous nutrition and medications, abdominal surgery, and finally a tracheostomy.

By the time Tommy went home at five months of age, he had already been transferred several times between the regional neonatal ICU and Children's Hospital which was halfway across the state. His mother had only been able to return to work one or two days a week and his father had to reduce his full-time college studies in order to care for family needs.

Doctors believed that surgery to rebuild Tommy's trachea was possible. They believed that by the time he was one or two he would essentially be normal. Based on this prognosis, Tommy's parents prepared to "get through" the next year or two.

Tommy came home to his family with a trach tube which was suctioned a minimum of four times an hour. He required "nippling" and gavage tube feedings every two hours, daily OT and PT regimes, and chest percussion every few hours. He needed constant assessment of his airway by skilled personnel, an apnea-heartrate monitor, a suction machine, a heated nebulizer and compressor, and emergency oxygen.

Only the services of a visiting nurse were arranged before Tommy left the hospital. Therefore, his parents provided around-the-clock care which necessitated that one or both of them sleep in a hide-a-bed in his "bedroom" in the family room. After a week and a parade of Public Health, Crippled Children, visiting nurse, and private duty agency personnel interviewing the parents and taking copious information, temporary nursing coverage was arranged. Then, as his father drove him to the emergency room, Tommy stopped breathing. He was taken by helicopter to Children's Hospital where he spent additional weeks.

The first year was tenuous with numerous life threatening events and was generally spent in the hospital. At one year of age, though he weighed only 12 pounds, he had reconstructive surgery. It was unsuccessful, had complications, and kept him in the hospital on his first birthday.

Though Tommy's gross motor skills were quite delayed, at no time was a referral to special education services made. Tommy's parents met other parents at Children's Hospital whose children received school-provided services. When they inquired with their hometown neonatal staff, they were told that Tommy was not developmentally disabled and therefore special education would not be available. His parents concluded that they were asking for services that were unnecessary.

At one and one half years of age, Tommy could communicate only by throwing his head back and refusing while his twin sister was beginning to talk. His parents knew that he understood language but saw increasingly negative behavior: Tommy began refusing to point to body parts and pictures in books and was very frustrated that his sister could talk and he could not. His otorhinolaryngologist did not want him to be taught signing, fearing he would "rely" on it after his trach was out. However, his parents insisted that he be tested. Following an evaluation at the hospital speech and hearing clinic at which the therapist could find no evidence of language skills, the speech pathologist recommended an

immediate referral to the ISD. Unfortunately, it was spring and the school year would be over by the time an individualized education program (IEP) could be completed. Therefore Medicaid/Crippled Children paid for speech therapy through the family's nursing service. Tommy immediately developed a 100-word signing vocabulary and frustration was significantly reduced.

In the fall, Tommy was evaluated for special education services. His parents were pleased with the preprimary evaluation team and the assessment which was provided. They did not understand the IEP process and, in retrospect, regretted its outcome. Their local district did not have a speech therapist who knew signing; therefore, a hearing impaired teacher consultant was assigned. This did not work well, however, because the teacher was not skilled in working with young children and she cancelled nearly half of the appointments.

During assessment for a new individualized educational planning committee (IEPC) meeting, the speech pathologist of the local clinic discovered that Tommy could make a little sound. They found that Tommy had receptive, and attempted expressive, language at a level two years beyond his chronological age. A very stressful IEPC meeting was held and the school agreed to contract with the clinic for speech therapy in the home or in the clinic depending upon Tommy's health status.

Tommy's parents felt they were continually trying to keep Tommy from being the square peg in the round hole of existing local and ISD "programs". They visited the preprimary speech impaired and "multiply handicapped" classrooms. This placement was recommended even though Tommy's pediatrician had indicated neither Tommy nor his sister could attend daycare or preschool programs because of the risk of infection. During this time, they learned about the special education laws and that they were their child's best advocate. They became full partners in negotiations relative to their son's future schooling. Their expectation for Tommy was that he would go to his regular community school with his sister.

There was reason to believe that Tommy would have his trach removed and that the only lasting damage would be that his vocal cords would be destroyed. Tommy's parents emphasized the importance of the best possible speech therapy for Tommy as a preschooler. After a year of therapy by the single speech therapist in the district, Tommy's family and physician successfully argued for specially contracted services to be provided by a speech therapist who had experience with trachs and voice disorders.

After another partially successful rebuilding of Tommy's trachea, Tommy's health declined. It was determined that Tommy would probably start kindergarten with a trach. A teacher was selected who had many of the same ideas as Tommy's parents and was open to communication with the parents. As summer ended, arrangements were made for location of supplies and equipment and the incorporation of the LPN aide, and a decision was made as to how to present information about Tommy's special needs to his peers and their parents.

Tommy's parents wanted him to ride the bus with the other students but the school refused busing due to liability issues. The parents dropped this request in consideration of their first priority -- school funded nursing. A health care aide with LPN skills was needed. While school staff were unavailable to discuss this need during the summer, near the start of school a candidate was selected. She had been recruited through word-of-mouth and had not practiced nursing for a number of years. Administrators were vague about how she would be trained and it eventually became clear that this responsibility would rest with the parents. The parents were also informed that when the aide was absent Tommy would not attend school since substitutes would not be available. This issue did not get resolved until mid-year.

The first year of school for Tommy in the "Young Fives" classroom was a success in the eyes of his parents. He was accepted by his peers. His teacher was convinced that a regular class was the place he belonged. Everyone in the building seemed to agree and his social skills improved.

The next year started badly, however. Without seeing him, the kindergarten teacher announced at the IEPC meeting that Tommy belonged in a place with "other children like him" because "the children would be mean to him." She also indicated that his parents should be "thinking of what's best for him and not just what they selfishly wanted".

When school started, the teacher refused to allow the suction machine and other equipment in the classroom, stating that the other children would be traumatized. The equipment was placed in the principal's office at the opposite end of the building. Tommy's physician wrote a letter emphasizing the need to place the equipment in the classroom. The teacher was not available to meet for weeks and finally Tommy's mother took a week from work to resolve the problem. Though a number of hurtful things were said during the process -- that "no one wanted the child" and "no one wanted to deal with his mother" -- the equipment was placed in the classroom. Healing began when a first grade teacher requested Tommy for the next year.

There are several processes that helped both Tommy and his parents in relation to his schooling. These include:

1. a teacher who "wants" the child;
2. early identification of the teacher for each year;
3. regular information sharing and an annual opportunity for building staff to ask questions about medical needs and accommodations;
4. annual parent/child visits to each class in the grade level to talk about the trach and suction machine, to encourage questions, and to model desired behavior;
5. administrators and parents listening and responding to the teacher's thoughts and needs for support;
6. as much honest praise as possible for whatever is done right and well by all parties;
7. strong administrative support;
8. acceptance of parental expertise,
9. a willingness to be creative and flexible;
10. strong special education laws; and
11. support of friends, neighbors and parents at the school.

In Tommy's family there have been many stresses as well as triumphs and joys. The greatest stress has been the constant worry about how to cover medical bills. At times the family has reached the lifetime limits of their private insurance coverage. Insurance needs for Tommy are closely tied to employment as well as to income options and limitations for the whole family.

Recent years have been successful ones. Tommy seems to be a good student with outstanding math ability. School personnel indicate that they feel good about the decision to have Tommy in their school and that his being there has helped other children with handicaps to be included.

Last spring, a family from another school district asked for insight into the process of placing their son in school. A visit to Tommy's school was arranged by the child's school team. Tommy and his family were gratified to hear school personnel report that Tommy's placement turned out to be one of the most successful things the school had ever done.

## Vignette II.

The following paragraphs are observations on the school experience of a student born with a rare form of muscular dystrophy. The student is presently 17 years old and a junior in high school. Because of the degenerative nature of her muscle disease, she has become a student who is now "technologically dependent" on oxygen and on the use of a negative pressure respirator. The respirator is used part of the day and through the night.

School has been an important aspect of her life as it should be for any young person. Her schooling started with a preschool program for physically impaired children run by the school district. In first grade, frequent respiratory infections and hospitalizations began to interfere with regular attendance at school. In second grade, she began to arrive at school in the late morning due to the need for extensive respiratory therapy at home. As her disease progressed, a program of partial class time and partial homebound work helped her keep pace with her peers. Because she is bright, the intellectual stimulation of school work has helped to focus her attention on something besides the increasing loss of physical abilities. It is the one arena where she can excel and where she can be like her peers, that is, doing the work they do.

Homebound work gradually became her only option as breathing difficulties and fatigue made it impossible for her to handle even limited class time. As she moved toward full-time homebound instruction, loss of daily contact with her peers was the most difficult adjustment. She still attends an occasional evening sporting or social event at school and is determined to graduate with her class. These goals have helped her fight depression over her losses and have helped her maintain a somewhat "normal" life.

Over the years, accommodations have been worked out with teachers, support staff, and administrators. During grade school, a physical therapist provided percussion and postural drainage therapy when this student needed to leave class due to breathing difficulty. Designated students began to help with handling heavy books and locating pencils out of reach as her physical abilities diminished. She began using a tape recorder for taking notes when writing ability decreased. During middle and high school, classes were shifted to more accessible rooms to accommodate her arrival in her wheelchair.

Hospitalizations have occurred periodically throughout these school years and are often of long duration. Hospital-bound instruction has been crucial in keeping her from falling behind and in keeping her in touch with the world of school. Caring teachers have helped her identify abilities and strengths in the midst of progressing disabilities. Ongoing communication between the student, her parents, teachers, administrators, support staff, and her doctor has been a key factor in maintaining her progress toward graduation.

### Summary Regarding Family Issues and Role of Parents

The State Medically Fragile Referent Group believes that parent involvement is key in planning for the individual child, program planning, and policy formation. From the documents reviewed, two excerpts seemed to be especially reflective of the message we want to convey about the role of parents.

- The Elements of Family Centered Care for Children with Special Health Care Needs (Association for the Care of Children's Health, Shelton, Jeppson, and Johnson, 1987) enunciates a philosophy which we recommend to all parties working with this population of children and families:

    1. Recognition that the family is the constant in the child's life while the service

systems and personnel within those systems fluctuate;

2. Facilitation of parent/professional collaboration at all levels of health care; care of an individual child, program development, implementation and evaluation, and policy formation;
3. Sharing of unbiased and complete information with parents about their child's care on an ongoing basis in an appropriate manner;
4. Implementation of appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families;
5. Recognition of family strengths and individuality and respect for different methods of coping;
6. Understanding and incorporating the developmental needs of infants, children, and adolescents and their families into health care (service) delivery systems;
7. Encouragement and facilitation of parent-to-parent support; and,
8. Assurance that the design of health care (service) delivery systems is flexible, accessible, and responsive to family needs.

- We felt the role of parents as participants in the planning of the school needs of their children with complex care needs can be best described as follows: Due to the parent or guardian's unique understanding of their child's needs and abilities, they will have an integral role in the planning process. They are the ultimate source of information and resources. Their role will include:

1. Advocacy on behalf of the child;
2. Providing access to health care providers;
3. Approval of the IEP or individualized family service plan (IFSP), Education and Health Care Plan(s), and Emergency Plan(s);
4. Notifying the (designated) school (contact) of changes in the student's condition or health care requirements;
5. Serving as a source of child-specific information and, when appropriate, training.

(Adapted from Children Assisted by Medical Technology in Educational Settings: Guidelines for Care, Project School Care, 1989, p 13)

## B. Interagency Recommendations

Medically fragile children often have a wide range of service needs. Given the potential of diverse and numerous different specialized service providers, interagency communication and coordination is imperative. The State Medically Fragile Referent Group makes the following recommendations regarding interagency coordination:

1. Identify a focal point for all State policies on medically fragile children and for information regarding resources for the care and development of medically fragile children.

2. Within Special Education Services at the state level, identify and support the development of expertise in one or more staff to serve as a resource to personnel in local districts and to parents. (This person or persons must have a firm understanding of the entire range of issues and policies that affect families of medically fragile children, not just those in the area of education.)

3. Identify for review and potential modification, any points or processes within the laws or guidelines of the Department of Education which may relate to medically fragile children (e.g., Child Find, ISD Plan Criteria, 99-457 planning, inclusive and integrated education initiatives, and so on).

4. Be aware of and utilize the expertise of specialized services outside of special education. (Examples include: Children's Special Health Care Services and its Specialized Home Care and Parent Participation Programs; Department of Mental Health and its Permanency Planning; Family support and Medicaid Waiver II Staff; Department of Social Services Medicaid and Parent Empowerment Programs; as well as the Office of Children and Youth Services and Medically Fragile Programs.)

5. Involve parents of medically fragile children and the affected young adults themselves as advisors on policy matters and compensate or reimburse families for expenses incurred in such consultation service; e.g. child care, travel, etc.

6. Ensure that the Department is involved in interagency activities and that it is aware and well informed regarding issues in other policy and program areas, including public programs in health, public mental health, social services, private health care providers, and private insurance trends.

7. Proceed very cautiously on third party reimbursement strategies (including Medicaid; Department of Mental Health Medicaid; Department of Public Health/Specialized Home Care "Waivers"; and family's private insurance), at both the State Department and local district level. (Attempts to capture reimbursement may have extremely negative consequences regarding availability of needed services in non-school settings. Family members' ability to remain employed and/or maintain insurance coverage may also be affected.)

8. Be especially aware of, and provide input to, early intervention activities for this population at the local and state level. (Increases in the medically fragile population are occurring in the younger age group. The Interagency Planning and Agreements related to 99-459, Part H, Services for Handicapped and At-Risk Infants and Toddlers, are expected to play a major role in efforts to coordinate agreements on reimbursement, case management, and service delivery.)

9. Pay particular attention to strengthening communication and collaboration between health care providers and the educational staff. Especially important is identifying clear roles and effective models for partnerships between the child's primary health care provider(s), family, and local school staff.

## Summary Regarding Interagency Collaboration

Because the needs of medically fragile children are so diverse and the service providers so specialized, it will be particularly easy for miscommunications, duplicity of effort, gaps in service, and general confusion to exist. For this reason the State Medically Fragile Referent Group recommends interagency communication and collaboration as critical to good service to students. They also recommend very careful identification and designation of areas/agencies of expertise, and both at the state and local level, the identification of key resource people to whom others may go and who will assist in coordinating the overall effort. The key in this effort seems to be inclusion of all appropriate expertise, assigning and focusing the energy and effort of personnel, and maximizing coordination of the information.

# Section IV

# Program Support Recommendations

## A. Specific Steps to Service Delivery

Medically fragile students represent an emerging population with a unique set of needs. These needs change continually with the advancements of technology, which impacts the development of educational plans, including curriculum and related services. In addition to individual student referral procedures, it is recommended that administrative and/or board consideration be given to the following issues:

1. Partnership with Families
   The needs of medically fragile students are complicated by the numerous health/service providers that are involved with the student. To obtain and assimilate the necessary health care information for initial and ongoing educational services it is imperative that a parent/school working partnership be established.

2. Staffing/Training/Equipment
   The needs of the medically fragile student may require unique staffing patterns, training, and equipment. School districts need to establish working agreements and partnerships with other community/agency resources in order to fully utilize these resources on behalf of the child.

3. Extraordinary Measures
   School district boards of education need to be prepared by having policies or clearly articulated board positions in place in order to guide district personnel in responding to the life threatening health conditions which may be encountered with this population. In particular district personnel need to know the district's position regarding parental "DO NOT RESUSCITATE" orders and other emergency procedures.

4. Service Delivery Considerations
   Once a contact is made with the school and a referral for services initiated, the school district needs to take the following steps as efficiently and effectively as possible:

   a) Identify the primary team of staff to handle the referral and placement of the student, designating a primary representative of the school system. (Note: It is important that the school representative has an opportunity to meet the family and other primary caregivers.) (Appendix: Important personnel - pg 22, Project School Care: Guidelines for Care.)

   b) In cooperation with the identified caregivers, determine the necessary information to be obtained to plan for placement and educational service delivery. Determine also the form/format and who should provide information in the following areas:
      - curriculum
      - medical/health
      - environment; school building, classroom, transportation
      - MET evaluation and schedule of the MET meeting

(Note: In communicating to the staff about the student, determine the staff response and concerns and meet as needed to provide inservice and/or review plans.) (Appendix: Letter to physician to obtain medical information (Vol.I. App.A, Form 2, Wayne County Doc.)

c) Assign staff responsibilities to obtain the necessary information, due date, and follow-up on returns.

d) Establish a meeting date to review the information in preparation for the IEP. (Note: Determine if the 30-day IEP requirement can be met. If not, take appropriate action. A checklist to monitor progress may be helpful.) (Appendix: Health Care Plan Checklist, Page 21, Project School Care: Guidelines for Care.)

e) Convene a program planning meeting for the purpose of reviewing all available information and determine if everything needed for placement and services has been obtained. The agenda may include the following items:
   - curricular recommendations
   - health and medical needs; medical procedures; frequency of procedures; risks/emergency procedures
   - environmental needs; classroom/school adaptations, transportation requirements

(Note: Parents, all pertinent caregivers, and other agency/health professionals should be invited to attend to ensure all needed information is available. This meeting could function as a multidisciplinary evaluation team (MET) meeting or a program planning meeting prior to an IEP. Determine the staff response and level of concern to the information presented. Provide followup as needed. (Appendix: Medically Fragile Review Committee Summary (App.C, Wayne County Doc.) (5 pgs) or Project School Care: Guidelines for Care, Pgs 23-29.) (Appendix: Educational Environmental Consideration (App. D, Wayne County Doc.)

   - staff competencies or safeguards needed; staff and/or equipment consultation, training materials, etc.
   - additional information needs prior to IEP meeting
   - appropriateness of IEP timeline
   - knowledge level of the staff and inservice needs
   - impact on existing board policies and procedures of particular child needs

(Note: The following policies and/or procedures may be typical of those reviewed: Health and Communicable Disease Policy, Safety (CPR; first aid), Emergency Procedures, Corporal Punishment, Suspension or Expulsion, Environmental Safety, Behavior Modification, Child Abuse or Neglect, Right to Know.)

f) Determine need for staff follow-up plans, concerns, and questions. Ensure that staff understand roles, responsibilities, and obligations.

g) Obtain remaining information. The coordinator of the placement process should conduct a follow-up on all information prior to the IEP.

h) Review possible placement options with the parent.

i) Convene the IEP and ensure that the following items are addressed and decisions made regarding:
   - curricular objectives (goals and short-term instructional objectives)

- medical needs:
  - equipment
  - staff
  - training
  - length of day
- classroom/school needs:
  - equipment
  - quick access to medical personnel (develop emergency plan when appropriate)
  - transportation

(Note: An extension on the IEP implementation should be obtained if necessary.) (Appendix: Conditions Necessary for Safe Transportation, App.C., Wayne County Doc.) (Appendix: pg 28, 29, Project School Care: Guidelines for Care)

- specific placement (Appendix: 13-Step LRE document)
- need for related services
- determine training needs for staff which includes the identification of trainers and the documentation of validated competencies

(Note: Refer to the training section of this document)

- necessary medical procedures and obtain appropriate authorization by parent/guardian and physician in order to implement the procedures.

(Note: Appendix: Medical Procedure Authorization (Vol I., App. D, Form 3, Transp. Study. Appendix: Page 31-32 Project School Care: Guidelines for Care)

- implementation timeline and assignments

(Note: Extended implementation timelines should be outlined if it is necessary to go beyond the 15-day limitation.)

- establish a communication system for notification of changes in student health status at school and/or home
- determine a plan for back up staffing and corresponding training needs

j) Provide for adaptations as specified in the IEP.

k) Implement the training as outlined by the IEP committee and provide documentation of competencies as outlined (general knowledge and specific skill training). Note: Refer to the Training Section of this document.

l) Place the student and implement program and services following an evaluation of all requirements that were outlined by the IEP. If problems occur, discuss them with the caregiver and other relevant individuals and determine the need to convene another IEP.

m) Review job roles, training, environmental factors, and institute changes in staff or transitions to new environments as needed.

## Summary Regarding Program Support

The State Medically Fragile Referent Group has recommended a set of specific services and check points, starting with a partnership with families, which will help districts move towards provision of services efficiently and effectively once a referral for services is initiated. Recommendations encourage systematic identification of primary teams and necessary information, assignment of responsibilities, activation of planning meetings, reviewing options and gathering missing information, making decisive programmatic decisions on a designated set of issues, implementing training, and placing the student with efficient implementation of the designed program. Again, the importance of systematic communication, coordination, and assignment of responsibilities is emphasized in order to manage the diversity of information and needs in this population.

## B. Transportation

### Introduction

Questions related to transporting medically fragile students are complex. Transportation is a related service for those students requiring it (Administrative Rule 340.1701(c)(iv)). Specialized transportation is defined as "transportation services provided in vehicles with or without the equipment necessary for the adequate and safe transportation of special education students" (Rule 380.51 (b)). This section of the report will identify information resources and summarize important basic processes for decision-making.

### Information Resources

There are several documents that contain useful information pertaining to the transportation of medically fragile students. For example, the "Report of the Council for Exceptional Children's Ad Hoc Committee on Medically Fragile Students" (March 1988) identifies the following considerations that must be addressed to provide safe and appropriate transportation:

- Eligibility for transportation and the mode of transportation should be determined by an interdisciplinary team;
- The need for transportation should not be contingent on eligibility for special education but be based on the most appropriate and safe way to transport a student to school;
- Criteria for transportation services should be individually determined;
- Transportation should be individualized for students with specialized health care needs;
- Modifications of traditional transportation vehicles is encouraged;
- Transportation personnel should be provided adequate training in transporting students with specialized health care needs. Training should include placing the student on and off the transportation vehicle and appropriate first aid procedures;
- All transportation vehicles shall have an emergency card for each student transported. This will expedite implementation of appropriate procedures and contacts in case of an emergency during transport; and,
- Written procedures for the transportation of students with specialized health care needs should be developed by appropriate personnel in all involved agencies. Such procedures should be conveyed to all involved in service delivery that includes transportation.

The Wayne Academy identified four conditions that must be addressed to assure safe transportation: tolerance for movement, special equipment necessary, vehicular design, and restraint systems.

The most comprehensive document to date addressing the vast array of issues related to transportation of medically fragile students is entitled, "Study of Transportation of Medically Fragile Children." This document was developed for Special Education Services, Michigan Department of Education, under a state initiated project. The report is dated April 17, 1989. The document is divided into four major volumes. Volume I addresses methodology, legal status, procedures, criteria, and recommendations. Volume II describes a variety of adaptive and support equipment. Volume III includes information pertaining to personnel qualifications and training. Volume IV specifies a health care curriculum for bus drivers and attendants.

## Basic Processes for Decision-Making

Information outlining how decisions on transportation for this population are made is essential. The process for decision making is best described in the "Study of Transportation of Medically Fragile Children," Volume I, pages 43-62. It should be noted, however, that some of the information contained in the outline of what transportation services the district is required to provide, versus the transportation services that a district is not required to provide, has changed as a result of litigation since the document was prepared. The legal review section of this report provides current information regarding this area.

The following section, summarized from "Study of Transportation of Medically Fragile Children," provides a listing of important information to be gathered and transportation decisions to be made:

1. When considering the placement of a medically fragile student, the multi-disciplinary evaluation team (MET) first needs to consider all of the available medical, parental, and educational data, and the impact of the transportation limitations. A physician needs to do the following in writing:

   - Confirm that the student is "medically transportable." The conditions under which such transportation could be safely undertaken should be provided in written form.

   - Identify the special medical problems, health concerns, or communicable diseases which would influence the student's transportation.

   - Identify the level of supervision required during transportation; specifically, intervention techniques and special equipment which may be needed, and the level of training required to initiate the specific interventions.

2. If a physician indicates that a) the student is "medically non-transportable," a home program for the student should be designed at the IEP, and if b) the student is "medically transportable," the IEPC should decide if risks in transporting are "justifiable" given the program(s)/service(s) the student would receive in school.

3. If such medical information is unavailable from the student's family doctor, the school district officials may need to contract with other appropriate medical authorities to acquire the needed information. If there is a disagreement between the parents and school district officials as to the medical information used, either party has the opportunity to seek an independent educational evaluation (IEE). It is suggested that the School District have access to its own medical consultant, who could further clarify the concerns of the family doctor or make independent medical judgments for safety matters. This individual may also be a valuable person responsible for training the district's instructional and transportation staff members.

4. Traditionally, school transportation staff members (and private transporters) have not been invited to MET or IEPC meetings. Due to the complex nature of transporting medically fragile students, this practice must change to include transportation staff members when such issues are to be addressed.

5. The "Michigan Department of Education's 13-Step Least Restrictive Environment (LRE) Policy" should be followed when considering the placement of any special education student. Particular attention must be paid to steps 2-4 and 7-9 when

addressing transportation issues for medically fragile students. A copy of this policy is contained in Appendix B of this report.

6. During the student's IEPC meeting, the items discussed at the student's MET must also be discussed. "The IEP must specify all of the special education services necessary to meet the student's special education and related needs" (Special Education Services Official Interpretation #052).

7. It is appropriate for a medical consultant, school nurse, or someone else knowledgeable about particular medical procedures to train all those service providers specified in the IEPC, including the student's teachers, related services personnel, paraprofessionals, and transportation staff members, on particular procedures to be used with the student.

### Summary Regarding Transportation

Transportation is a related service which must be considered when planning for educational service to medically fragile students. The "Report of the Council for Exceptional Children's Ad Hoc Committee," the report from the Wayne Academy, and the "Study of Transportation of Medically Fragile Children" prepared for Special Education Services provide additional helpful information and are recommended for review. There are key decisions that need to be made when planning transportation for this population. Information from medical and transportation personnel is critical to the planning and decision process.

## C. Nursing

Recent court cases have clearly defined the school district's role as provider of education for all children, including those considered medically fragile and/or technology dependent. With the introduction of more children who require special medical and health management, districts need to develop policies and procedures regarding the delivery of services in order to support and guide their staff. School district personnel should be aware of the implications of performing health/medical procedures which fall within the domain of licensed health care professionals, before they embark on the task of establishing their policies and procedures. The following identify key issues related to one element of program support -- the practice of nursing:

1. The Nurse Practice Act is a statute which delineates the legal scope of the practice of nursing within specific geographical boundaries ("Report on the Delineation of Roles and Responsibilities for the Safe Delivery of Specialized Health Care in the Educational Setting", November 15, 1989). The legal framework for nursing in Michigan is found within the Public Health Code, PHC 368. This act controls the practice of nursing and regulates those nurses licensed to practice the profession within Michigan.

2. A registered nurse (RN) is identified as a licensed health care professional who is legally licensed to practice by state authority. Registered nurses are accountable for their own actions in nursing and, therefore, have an obligation to practice at all times within the scope of their current range of education, knowledge, skill, and experience (Michigan Public Health Code: Definition of Nursing, Guy, Joan, RN, The Michigan Nurse, April, 1981, p 4-6). An LPN (licensed practical nurse) is licensed to administer care under the direction of a registered nurse, physician, or dentist. (P.A. 368).

3. In Michigan the practice of nursing means "the systematic application of substantial specialized knowledge and skill, delivered from the biological, physical, and behavioral sciences, to the care, treatment, council and health teaching of individuals who are experiencing changes in the normal health processes or who require assistance in the maintenance of health and the prevention or management of illness, injury or disability" [P.A. 368, 333.17201, Sec. 17201 (1)]. "The practice of nursing as a licensed practical nurse means the practice of nursing based on less comprehensive knowledge and skill than that of a registered professional nurse..." [P.A. 368, 333.17208, Sec. 17208].

4. A licensee (e.g., RN) who holds a license other than a health professional subfield license (e.g., LPN) may delegate to a licensed or unlicensed individual who is otherwise qualified by education, training, or experience the performance of selected acts, tasks, or functions where the acts, tasks or functions fall within the scope of practice of the licensee's profession and will be performed under the licensee's supervision. An act, task, or function shall not be delegated under this section, which under standards of acceptable and prevailing practice, requires the level of education, skill, and judgment required of a licensee under this article [MCL 333.16215 (1)].

5. The Public Health Code does not identify those acts, tasks, or functions that must be performed by an RN, but rather relies on current standards of practice. Standard of practice means that which is established by custom or authority as a model, criterion, or rule for comparison or measurement ("Report on the Delineation of Roles and Responsibilities for the Safe Delivery of Specialized Health Care in the

Educational Setting", November 1989). Standards of practice for RNs and LPNs has evolved in Michigan based upon the criteria for reimbursement from insurance companies and Medicare/Medicaid.

6. In 1972, amendments to the Social Security Act established a single common definition of care requirement for skilled nursing under Medicaid and Medicare. The Michigan Department of Social Services has delegated to the Department of Public Health the responsibility of establishing examples of acts, tasks, or functions requiring the skills of an RN or LPN for reimbursement purposes (Department of Public Health Letter 25-4 Revised). It includes such procedures as:

   A. Intravenous, intramuscular or subcutaneous injections;
   B. Levene tube and gastrostomy feedings;
   C. Naso-pharyngeal and tracheostomy suctioning;
   D. Insertion, sterile irrigations, and replacement of catheters; and,
   E. Application of dressings, requiring aseptic techniques, etc.

7. Hospitals, nursing homes, and other health care providers establish criteria for levels of care based upon the standards they must meet for reimbursement from third party payers. There is an absence of specific language within the Public Health Code. Perhaps this absence requires institutions to set their own standards for practice. School districts must determine to what extent they can assume the financial cost of full-time nurses or can assume legal liability for medical care during school hours.

8. The American Nurses Association Division on Nursing Practice states: "Without school nursing services, school personnel, including classroom teachers, for example, face serious risks if they assume responsibility for the performance of complicated health procedures for which they are neither prepared nor licensed, but which are necessary if students with certain handicaps are to receive the education to which they are entitled. Under the related services provision of this act, 300.12, handicapped children are entitled to school health services provided by qualified school nurses" ("School Nurses Working With Handicapped Children," A Statement of the American Nurses' Association Division on Nursing Practice).

9. In November 1989, the Council for Exceptional Children (CEC) published the "Report on the Delineation of Roles and Responsibilities for the Safe Delivery of Specialized Health Care in the Educational Setting." It lists health care procedures performed in schools today and recommends the persons who should and are qualified to perform each procedure.

**Summary Regarding Nursing**

The State Medically Fragile Referent Group recommends that as districts embark on development of support services for medically fragile students, they pay particular attention to currently available information about the practices of nursing in schools. Specifically noted are the Nurse Practice Act, which controls the practice of nursing in Michigan; the Michigan Public Health Code, which provides definition of nursing activities and qualifications; P.A. 368, which defines licensed practical nursing duties and requirements; the 1989 CEC "Report on the Delineation of Roles and Responsibilities for the Safe Delivery of Specialized Health Care in the Educational Setting;" the Macomb ISD 1991 case; and others. Nursing services are considered a very important part of the support system for medically fragile students. Districts are encouraged to stay current and knowledgeable as to what services may and may not be provided by nursing staff.

## D. Staff Training

Training of staff and caregivers is the key to assuring the ability of the educational setting to accommodate the student as safely as possible. Training should occur on several different levels from general information to school staff to child-specific techniques for direct caregivers. This process does not end with the child's entrance into school. Regular review and update of skills should occur (Guidelines For Care, Project School Care: Children's Hospital, Boston, 1989).

Once a school has established a standard of practice, a training program should be designed and implemented at the various levels necessary to safely provide the required related medical services for the student(s). At each level of training, school personnel should meet pre-determined levels of competence in the given skill(s)/procedure(s). It is also recommended that the policy provide for continued reevaluation and ongoing training to update and maintain these competencies. A listing of resource information and persons can be found in Appendix B.

The "information level training" should include in-service for all school employees, including boards of education, administrators, transportation personnel, teaching staff, support staff, students, substitute staff, parents and volunteers. information regarding definition of medically fragile/technology dependent, demographics, legal perspectives, and examples of possible medical/health conditions should be addressed at this meeting.

The "general staff training" level should be initiated for all the building staff at the time a specific student is identified. Personnel who should attend this level of training include building administrators, teachers, ancillary and support staff, transportation personnel, and any other building/school employee who would have contact with the student(s). Training should include information regarding the student's condition and specialized medical care needs; understanding of human anatomy and physiology as it relates to the student's condition(s); a detailed review of the student's health care/management plan; delineation of staff roles and responsibilities in both daily and emergency situations; and transportation issues.

Policies regarding the delivery of specific medical/health care procedures may vary. Nevertheless, child specific technical training is appropriate for all staff who work directly with the student so that maximum care can be provided in the event of an emergency. This level of training should involve the parents, who are generally expert in child specific techniques, and should include not only the designated service provider, but also the building administrator, teacher(s), instructional assistant(s), aides, bus driver(s), and monitor(s). It should provide:

- indepth understanding of the student's condition and specialized medical/health care needs;
- human anatomy and physiology as related to the student's condition;
- instruction in the specific medical skills/procedures required for care of the student;
- demonstrated proficiency in the specified medical skill/procedure(s) required for the care of the student;
- identification of behaviors/symptoms which might indicate a problem requiring more advanced technological support, e.g., EMS; and
- review of the student's health care plan and emergency protocol.

Training at this level must provide for a regular schedule of reevaluation, retraining and skill updating to ensure continued proficiency for safe delivery of the required related services.

## Summary Regarding Staff Training

Staff training is considered an integral part of successful programming for medically fragile students. Information must be shared in order to reduce staff fear and misinformation regarding the student's behaviors and needs. Training is also required to maintain an adequately informed and skilled staff. Three levels of training are discussed: information level training, general staff training, and child specific technical training. For each level, the report identifies those people most appropriate to receive the training and the type of content that should be covered.

## Section V

## Appendices

## Appendix A
## Bibliography

### References for Perspectives on Educating Medically Fragile Students


1. "Current Perspectives on the Education of Medically Fragile Students: A Special Focus Report", February, 1989. (Prepared by the Center for Quality Special Education)

2. "Medically Fragile" Handicapped Children: A Policy Research Paper (prepared by Great Lakes Area Regional Resource Center, May, 1986)

3. "Medically Fragile Subcommittee Report", March, 1989. (Prepared by the Wayne Intermediate School District)

4. "Report of the Census of Children with Complex Health Care Needs and the Survey of Families Who Care for Them", July, 1989. (Prepared by Health Management Associates, Inc.)

5. Report of the Council for Exceptional Children's Ad Hoc Committee on Medically Fragile Students (March, 1988).

6. Report of the Office of Technology Assessment on Technology Dependent Children, Washington, D.C. 1987.


Other sources reviewed include the Jackson Intermediate School District Medically Fragile Procedure (draft, 9/89); Study of Transportation of Medically Fragile Children ( 4/17/89); Lyn Beekman's Report to Wayne Intermediate School District Superintendent's Group entitled, "Provision of Services to Medically Fragile Students" (10/89); MAASE Subcommittee Executive Summary: Medically Fragile Survey (10/10/89; Patricia McQuarrie, chairperson).

### References for Training

The following have been reviewed and found to have value as possible sources for developing procedures and/or policies regarding training in specific medical/health procedures for school employees. Some references may also provide a basis for developing a process for the evaluation of employee competence in a given procedure(s). However, it should be noted that no one reference is complete. Therefore, schools may wish to draw from several of the sources in compiling their training manual and evaluation guidelines. References indicated with an asterisk (*) have been found to be most informative.

**Books**


Adamo, P. A. (1981). A Guide to Pediatric Tracheostomy Care. Springfield, IL: Charles C. Thomas.

Bulau, J. M. (1986). Clinical Policies and Procedures For Home Health Care. Rockwell, MD: Aspec Publishers, Inc.

Caldwell, T., Todare, A. & Gates, A. J. (Eds.) (1989). Community Provider's Guide: An Information Outline for Working with Children With Special Health Care Needs. Bureau of Maternal and Child Health Resources Development, Grant #MCJ223631. New Orleans: Children's Hospital.

California State Department of Education (1983). Guidelines and Procedures For Meeting the Specialized Physical Health Needs of Students. Sacramento, CA.

Ellmeyer, P. & Thomas, N. J. (1982). " A guide to Your Patients Home Use of Oxygen". Nursing, 82, 56-57.

Haynie, M., Porter, S. & Palfrey, J. S. (1989). Children Assisted by Medical Technology in Educational Settings: Guidelines for Care. Boston, MA.: Project School Care, The Children's Hospital.

Lewis, K, & Thomason, H. (1986). Manual of School Health. Menlo Park, CA: Addison-Wesley Publishing Company.

Meyers, D. (1989). Client Teaching Guides for Home Health Care. Rockwell, MD: Aspen Publishers, Inc.

Michigan Association of School Nurses (1988). Special Education School Nurse Procedure Manual. East Lansing, MI.

Michigan Department of Education, Special Education Services. (1989). Study of Transportation of Medically Fragile Children. Lansing, MI: Volume IV, pp.1-190.

Walsh, J., Persons, C. B. & Wieck, L. (1987). Manual of Home Health Care Nursing. Philadelphia, PA: J. B. Lippincott Company.

Whitesel, E., Carlin, P. & Amo, D. (1982). "Getting It Started and Keeping It Going: A Guide For Respiratory Home Care of the Ventilator-Assisted Individual". New Orleans, LA: Children's Hospital

*Wong, D. L., Whaley, L. F. (1986). Clinical Handbook of Pediatric Nursing. St. Louis, MO: C. V. Mosby Company.

VanderVeen, J. (1990). Criteria for Procedures. Ann Arbor, MI: Washtenaw Community College Nursing Program.

Viele, E. (1988). Procedures Guidelines for Health Care of Special Needs Students in the School Setting. Colorado Department of Education, Colorado, Department of Health.

**Bibliographies**

Federation for Children with Special Needs
312 Stuart Street
2nd Floor
Boston, MA 02116
(617) 482-2915

**Technical Assistance**

National Center for Providing Technical Assistance to Other States. Several training manuals also available.

Terry H. Caldwell
Education Consultant
National MCH Center
Children's Hospital
200 Henry Clay Avenue
New Orleans, LA 70118
(504) 896-9286 or 9287

## Appendix B
## Related Documents

### Visual Resources

* Key for Source:

{V} = The Video Source Book
{L} = Lansing District IMC
{R} = REMC
{ECM} = Epilepsy Center of Michigan

** Key for Format:

B = Beta
V = VHS
3/4U = 3/4" U-Matic
16M = 16 mm
8M = 8 mm
FC = Filmstrip & Cassette
MD = Microcomputer disk
MP = Motion Picture
Cable Video Tape = Call cable office for scheduling (517) 887-3051

*** Key for Acquisition:

R = Rent
P = Purchase
S = Subscription
FD = Free Duplication
FS = Free Loan

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*** Airway Management and Artificial Respiration (1985)**
This program shows airway management and artificial resuscitation including mouth-to-mouth resuscitation, bag-mask resuscitation and endotracheal intubation.

{V}76055, 24 minutes, C, B, V, 3/4U, FO, R, P (Ohio State University College of Medical-Medical A.V. & TV Center, 1583 Perry Street, Columbus, Ohio 43210)

*** Airway Obstruction and Pulmonary Arrest (1974)**
Deals with anatomy of the respiratory system, focusing on identification, purpose and function of parts. Demonstrates three methods of resuscitation. From "Medical-Legal Component Film" series.

{V}24195, 46 minutes, C, B, V, 3/4U, FO, P (National Audio Visual Center, (301) 763-1896)

*** Allegies (1983)**
This tape offers a complete overview of allergies and their treatment.

{V}75050, 42 minutes, C, B, V, 3/4U, P (Filmmakers Library, (212) 355-6545)

***Allegies -- Nothing to Sneeze At (1980)**
This segment of the "Once of Prevention" series explains that allergies are the leading chronic disease of children. This show describes common allergies, along with ways to pinpoint an allergy through skin tests and elimination diets.

{V}28947, 30 minutes, C, 3/4U, FO, R,P (Campus Film Distributors Corporation, (914) 961-1900)

*** Allergy (1975):**
The numerous substances most commonly causing allergies and hay fever are explored, as well as the problems of asthma and the ways of living with these ailments.

{V}26639, 10 minutes, C, B, V, 3/4U, R, P (Professional Research, 1-800-421-2363)

*** Allergy? Aller-Choo! (1982)**
This program from the "healthwise" series explains what allergies are and how to prevent and treat them.

{V}63656, 15 minutes, C, B, V, 3/4U, FO, R, DL, P (Coronet/MTI Film and Video, 1-800-621-2131)

*** Bleeding: What To Do (1973)**
When someone is hurt, what you do in the crucial moments before help arrives can mean the difference between life and death. Animation, models and reenactments are used to illustrate physiology, main pressure points and effective first aid techniques. Easily recognizable signs of arterial, surface, and internal bleeding are illustrated and explanations are given on how to treat each type.

{L}4042-02, 16 minutes, C, 16M, FL (Phramid Film and Video, 1-800-421-2304)

**Bronchial Asthma (1991)**
Discusses the various causes of bronchial asthma and differentiates between juvenile and adult cases. Animation demonstrates mechanics of the way the lungs work normally and during an attack. Emphasizes preventive measures to avoid or minize asthma attacks.

{V} 10 minutes, R, R (Milner-Fenwick, 1-800-432-8433)

**Cardiopulmonary Resuscitation (1983)**
A review of basic CPR maneuvers necessary to restore and maintain the pumping action of the heart.

{V}79992, 42 minutes, C, B, V, 3/4U, R, S, P (Emory Medical TV Network, (404) 727-5817)

**Cerebral Palsy (1978)**
This program is designed to introduce the physical therapy student to the general category of disorders referred to as cerebral palsy. It describes the classification, etiology and treatment of cerebral palsy.

{V}34048, 12 minutes, C, B, V, 3/4U, R, S, P (Health Sciences Consortium, (919) 942-8731)

**Changing a Colostomy Bag (1991)**
By providing a step-by-step description of the procedure and itemizing the equipment and supplies required, this program simplifies this process. Illustrates tye types of colostomies. Instructs the viewer how to teach the patient to change bags.

{V}9975, 30 minutes, P (Altschul Group Corporation, 1-800-421-2363)

**Choking (1980)**
Gives emergency first aid procedures for a conscious victim of choking and procedures for special circumstances such as infants and small children.

{L}5203-02, 13 minutes, C, 16M, FL

**CPSR for Citizens (1978)**
Aimed at the non-medical viewer, this film shows basic techniques for emergency care of heart attack and choking victims that will allow the person at the scene of an attack to keep the victim's heart pumping and brain alive until help arrives. Includes: ABC's of CPR, two-rescue CPR, CPT for infants and first aid for choking.

{L}4559-03, 25 minutes, C, 16M, FL

**CPR: Life At Stake (1978)**
Shows how to recognize cardiac arrest and how to resuscitate victims and the basic technique of CPR.

{L}4596-02, 21 minutes, C, 16M, FL

**Designing an Accessible Environment (1991)**
A framework for the assessment and modification of the environment to increase accessibility is presented. Professionals discuss the seven steps involved and emphasize that "barrier free" design allows social and psychological access as well as physical mobility.

{V} ME-3030, 14 minutes, P (Altschul Group Corporation, 1-800-421-2363)

**Diabetes (1972)**
This program explains the symptoms and complications of diabetes and how the disease can be controlled.

{V}21866, 30 minutes, C, V, 3/4U, R, FD, P (Abbot Laboratories, (312) 937-3933)

**Diabetes (1986)**
For the afflicted layman, the basic working of diabetes, its treatment and management is presented.

{V}94131, 25 minutes, C, B, V, 3/4U, P (American College of Physicians, 1-800-523-1546)

**Diabetes: Head to Toe (1979)**
This program examines essential ingredients of "total body care" programs for people with diabetes beyond diet, medication, and urine testing.

{V}43056, 11 minutes, C, CV, B, V, 3/4U, R, P (Professional Research, 1-800-421-2363)

*** Diabetic Care for Children (1986)**
The treatment and management of insulin-dependent children.

{V}90624, 50 minutes, C, B, V, 3/4U, R, S, P

**Epilepsy: A Comprehensive Approach for Nurses (1978)**
A series (7 programs) designed to increase knowledge of current concepts of the diagnosis, treatment, and long term management of epilepsy.

1. Medical Aspects of Epilepsy
2. Psychological, Social and Legal Implications of Epilepsy
3. Anticonvulsant Therapy
4. First Aid for the Epileptic
5. Status Epilepticus
6. Seizure Observation
7. Community Resources for People With Epilepsy

{V}51526, 40 minutes, C, 3/4U, P (University of Minnesota, Minneapolis, (612) 373-8973)

**Epilepsy: First Aid for Seizures (1980)**
The characteristics and appropriate first aid for absence, generalized tonic-clonic and complex partial seizures are demonstrated in this program.

{V}51527, 12 minutes, C, B, V, 3/4U, P (University of Minnesota, Minneapolis, (612) 373-8973)

**Epilepsy: First Aid for Seizures (1982)**
This program provides straight forward discussion about the various types of first aid for different epileptic seizures; how and whom to inform about an epileptic condition; and handling the reaction of bystanders.

{V}69357, 16 minutes, C, B, V, 3/4U, P (Centron Films, 1-800-621-2131)

**Epilepsy: First Aid for Seizures (1980)**
Video shows a young man who has a generalized tonic clonic (grand mal) seizure in a restaurant; a child experiencing absence (petit mal) seizures in school; and a factory worker having a complex partial (psychomotor) seizure.

{EMC}, 16 minutes, V, R

**Epilepsy Is... (1979)**
Two programs which demonstrate what happens when a person has a seizure, tell why it happens, and show how to give the appropriate aid and support. Tape I is designed for children, tape II for adults.

{V}51528, 13 minutes, C, 3/4U, R (University of Minnesota, Minneapolis, (612) 373-8973)

*** Epilepsy: The Child and The Family (1986)**
A presentation for parents produced by the Epilepsy Foundation of America. Epilepsy, its treatment and social aspects are introduced.

{ECM}, 15 minutes, B, V, R

**Epileptic Seizure Patterns (1963)**
A look at actual patients in a state of seizure and a description of the different types.

{V}04970, 25 minutes, C, 3/4U, FO, R, P (Indiana University Audio Visual Center, (812) 335-8087)

**Family Relationships in Home Care (1991)**
Living with a technologically assisted child can cause a great deal of stress on family members. Marital relationships, sibling relationships, and parental relationships may all suffer. This program presents frank discussions about what stresses can be expected, what the effects of the stress may be, and how to deal with these problems in an effective, healthy manner.

{V} ME-3028, 19 minutes, P (Altschul Group Corporation, 1-800-421-2363)

**First Aid Action (1974)**
Explains and demonstrates the most important first aaid techniques for the most common emergency situations. A spectacular sequence of sports accidents -- from auto racing to water skiing--introduces the need for first aid skills at home, work and play. Details are dramatized and on-camera narration by Burt Reynolds and first aid experts show how to handle each.

{L}4039-02, 22 minutes, C, 16M, FL

**First Aid: Newest Techniques, Part 1 (1974)**
Artificial respiration, bleeding, poisoning and shock.

{L}882-16, C, FC, FL

**First Aid: Techniques, Part 2 (1974)**
Burns, fractures, rescues, transfers and review

{L}883-16, C, FC, FL

**Home Medical Equipment Providers (1991)**
Contracting for technology support services can present many difficulties for the consumer. This program instructs viewers about what services are available and what criteria should be considered when selecting a supplier of home medical equipment.

{V} ME-3029, 15 minutes, P (Altschul Group Corporation, 1-800-421-2363)

**Hydrocephalus and Ventricular Shunts (1982)**
This program uses illustrations and CT scans in a comprehensive discussion of causes and treatment of hydrocephalus.

{V}60106, 51 minutes, C, B, V, 3/4U, R, S, P (Emory Medical TV Network, (404) 727-5817)

**Immune Response and Immunization (1985)**
Provides an opportunity to look at the nature of the immune response and immunization in the human body. Explains how AIDS and genital herpes elude the immune response. Vaccines of serum containing antibodies provide temporary "passive" immunity. Vaccines of weakened pathogens which cause the body to make its own antibodies without conferring the disease provide long lasting "active" immunity.

{R}MP0644, 16 minutes, C, MP

**Only a Breath**
Ventilator-assisted children, their parents and siblings describe their experiences and struggles to live with the technology. They identify problems with support systems as well as the effects of these problems on each member of the family.

{V} ME-8325, 30 minutes, P (Altschul Group Corporation, 1-800-421-2363)

*** Ostomy (1972)**
A comprehensive series (six programs) on the understanding of various surgical procedures, the techniques for using a variety of appliances and the necessity of good post-operative management to maximize the patient's well being.

1. Learning About Your Colostomy
2. Colostomy Care At Home
3. Learning About Your Illeostomy
4. Illeostomy Care At Home
5. Learning About Your Urostomy
6. Urostomy Care At Home

{V}54930, 15 minutes, C, B, V, 3/4U, P (Trainex, 1-800-854-2485)

**Ostomy: A New Beginning (1972)**
Deals primarily with the psychological aspects of having an ostomy -- an operation to create an artificial anus -- as experienced by actual ostomates.

{V}36397, 15 minutes, C, B, V, 3/4U, P (Milner-Fenwick, 1-800-638-8652)

**Our Friend EDI (Juvenile Diabetes) (1991)**
Educating children about disease is never easy. An animated pixie named Edi helps patients and their parents understand what diabetes is and how exercise, diet, and insulin will control diabetes. Edi and his friends review the need for insulin and blood glucose monitoring.

{V} DB-01, 10 minutes, R, P (Milner-Fenwick, 1-800-432-8433)

**Parents and Nurses: Separate Roles, Common Goals (1991)**
Conflicts between families and home nurses are inevitable. This program presents interviews with family members and nursing professionals who discuss the problems, benefits, and limitations of home care. The candor and honesty of the presentation will help viewers know what to expect and how to deal with difficult situations.

{V} ME-3027, 15 minutes, P (Altschul Group Corporation, 1-800-421-2363)

**Scoliosis (1976)**
Defines and describes what scoliosis is and how it can lead to critical disabilities unless detected and properly treated at an early age. Demonstrates step-by-step 30-second scoliosis detection techniques and familiarizes examiners with the indications of scoliosis deformity.

{R}MP2087, 14 minutes, C, MP

*** Tracheostomy Care (1971)**
A look at the most critical procedures in the care of the tracheostomized patient -- maintenance of the airway.

{V}54986, 25 minutes, C, B, V, 3/4U, R, P (Trainex, 1-800-854-2485)

**Tracheostomy Care (1971)**
This program provides nurses with instructions for the proper care of patients with endotracheal tubes and tracheostomies.

{V}64688, 22 minutes, C, B, V, 3/4U, R, S, P (Health Communications Network, (803) 729-4435)

**Tracheostomy Care -- The Cuffed Tube (1971)**
This program outlines the care of the tracheostomy patient who is on controlled ventilation.

{V}55231, 25 minutes, C, B, V, 3/4U, R, P (Trainex 1-800-854-2485)

**Tracheostomy Suctioning (1985)**
Health care professionals are taught how to perform and assess tracheostomy procedures.

{V}86452, 6 minutes, C, B, V, 3/4U, R, P (Intercollegiate Center for Nursing Education, (509) 326-7270)

**Ulcerative Colitis (1991)**
Reassures patients that even though IBD has no known cause or cure, the disease can be treated and they can continue to lead relatively normal lives. Reviews possible tests, medications, surgery, and dietary changes.

{V} 17 minutes, R, P (Milner-Fenwick, 1-800-432-8433)

**Ventilator Management (1975)**
The procedures for initiating long term mechanical ventilation are described.

{V}77092, 14 minutes, C, 3/4U, P (Center for Educational Development, (312) 996-7912)

**Resources for Training School Employees**
(Please note that parents are an invaluable resource of information and training in many of these areas as well.)

| Health Care Concerns | Resources for Training |
|---|---|
| 1. Airway Management | |
| Ventilator | * Respiration Therapist |
| Oxygen | * EMS |
| Tracheostomy | * Hospital |
| Nebulizer | * Nurse |
| Suction | * Physician |
| Postural Drainage | * Public Health Department |
| Percussion | |
| 2. Bladder/Bowel | |
| Catherization | * School Nurse |
| Crude | * Public Health Department |
| Anal Digital Stimulation | * Physician |
| Ostomy Care | * Hospital |
| 3. CPR/Heimlich | * Red Cross<br>* EMS<br>* Certified CPR Instructor<br>* Physician and/or Hospital<br>* Public Health Department<br>* Respiration Therapist |
| 4. Communicable Diseases | |
| CMV | * School Nurse |
| Aids/HIV Positive | * Public Health Department |
| Hepatitis A & B | * Center for Communicable Diseases |
| Common Childhood Diseases | * Physician |
| Congenital Herpes | |
| Turburculosis | |
| 5. Feeding & Total Parental Nutrition | |
| Gastrostomy Tube | * Physician |
| Gastrostomy Feeding Button | * Nutritionist |
| Nasogastric Tube | * School Nurse |
| Jejunostomy Tube | * Occupational Therapist<br>* Speech Therapist<br>* Public Health Department<br>* " Ostomy" Nurse |
| 6. Chronic Medical Condition | |
| Allergies | * School Nurse |
| Diabetes | * Physician |
| Cardiovascular | * Public Health Department |
| Autoimmunity | * Physical Therapist |
| Decubitus | * Occupational Therapist |
| Neuro Muscular Disorder | * Hospital |
| Heart Defects | |
| Shunts | |
| Head Injuries | |
| Orthopedic Implant(s) | |

| | |
|---|---|
| Degenerative Disorder<br>Temperature Control Disorder | |
| 7. Administration of Medication | * Physician/School Nurse<br>* Public Health Department |
| 8. Seizure Disorder | * Physician/School Nurse<br>* Public Health Department<br>* Epilepsy Center |
| 9. Universal Precaution<br>Handwashing<br>Body Fluids | * Public Health Department<br>* School Nurse<br>* Center for Communicable Diseases |
| 10. First Aid | * Red Cross<br>* Certified First Aide Instructor<br>* Nurse |
| 11. Physical Management Issues<br>Position and Lifting | * Occupational Therapist<br>* Physical Therapist<br>* School Nurse/Physician |
| 12. Behavior Management | * Psychologist/Psychiatrist<br>* Social Worker<br>* Teacher |
| 13. Equipment: Adaptive Life Support, i.e. (Communication Devices, Apnea Monitor)<br>Safe Use of Equipment<br>Maintenance | * Occupational Therapist<br>* Physical Therapist<br>* School Nurse/Physician<br>* Speech Therapist<br>* Hospital Rehabilitative Centers<br>* Equipment Vendors |
| 14. Stress Management/ Coping Mechanisms | * Social Worker/Psychologist<br>* Experienced Teacher<br>* Hospice |